

A SELECTION OF TEN READINGS ON TOPICS RELATED TO PERSONS WITH INTELLECTUAL DISABILITIES 2

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Selection of readings made by A/Prof Goh Lee Gan

READING I – INTELLECTUAL DISABILITY AND CARDIOVASCULAR DISEASES – DENMARK

Wang H,^{1,2} Zhang J,^{1,2} Lee PMY,³ Svendsen K,⁴ Li F,⁵ Li J.^{6,7,8} Association of intellectual disability with overall and type-specific cardiovascular diseases: a population-based cohort study in Denmark. *BMC Med.* 2023 Feb 6;21(1):41. PMID: 36747218.

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Author information:

¹MOE-Shanghai Key Laboratory of Children's Environmental Health, Xin Hua Hospital Affiliated to Shanghai Jiao Tong University School of Medicine, Shanghai, China

²School of Public Health, Shanghai Jiao Tong University School of Medicine, Shanghai, China

³Department of Clinical Medicine-Department of Clinical Epidemiology, Aarhus University, Olof Palmes Alle 43-45, 8200, Aarhus N, Denmark

⁴Research Unit for General Practice, Aarhus University, Aarhus, Denmark

⁵MOE-Shanghai Key Laboratory of Children's Environmental Health, Xin Hua Hospital Affiliated to Shanghai Jiao Tong University School of Medicine, Shanghai, China. feili@shsmu.edu.cn

⁶Department of Clinical Medicine-Department of Clinical Epidemiology, Aarhus University, Olof Palmes Alle 43-45, 8200, Aarhus N, Denmark. jl@clin.au.dk

⁷State Key Laboratory of Reproductive Medicine, Nanjing Medical University, Nanjing, China. jl@clin.au.dk

⁸Department of Epidemiology, School of Public Health, Nanjing Medical University, Nanjing, China. jl@clin.au.dk

ABSTRACT

BACKGROUND: Individuals with mental health problems have been shown to have an increased risk of cardiovascular disorder (CVD), but little is known about the risk of early-onset CVD among those with intellectual disability. We aimed to investigate the association between intellectual disability and subsequent CVD, taking into consideration the severity of intellectual disability and neurodevelopmental and neurologic comorbidity.

METHODS: This population-based cohort study used individual-level linked data from Danish national health registries. Participants were all live-born singletons born in Denmark during 1978-2016 (n=2,288,393). Follow-up began from birth and continued until the onset of CVD, death, emigration, or 31 December 2018, whichever came first. Clinical diagnosis of any CVD or type-specific CVDs was identified in the Danish National Patient Register. Time-varying Cox regression analyses were used to estimate the hazard ratio (HR) of intellectual disability associated with overall and type-specific CVDs.

RESULTS: A total of 11,954 individuals received a diagnosis of intellectual disability (7,434 males and 4,520 females). During a median follow-up time of 18.5 years (interquartile range, 18.1 years), 652 individuals with intellectual disability (5.5%) received a diagnosis of CVD (incidence rate, 2.4 per 1,000 person-years), compared with 78,088 (3.4%) CVD cases in individuals without intellectual disability (incidence rate, 1.9 per 1,000 person-years), corresponding to a HR of 1.24 (95% CI, 1.15-1.34). Increased risks of CVD were similar in both childhood (HR, 1.24; 95% CI, 1.08-1.43) and early adulthood (HR, 1.25; 95% CI, 1.14-1.38). For type-specific CVDs, intellectual disability was significantly associated with cerebrovascular disease (HR, 2.50; 95% CI, 2.02-3.10), stroke (HR, 2.20; 95% CI, 1.69-2.86), heart failure (HR, 3.56; 95% CI, 2.37-5.35), hypertensive disease (HR, 1.30; 95% CI, 1.22-1.39), and deep vein thrombosis (HR, 2.10; 95% CI, 1.60-2.75). Stratified HRs of overall CVD were 1.14 (95% CI, 1.01-1.30) for borderline/mild intellectual disability, 1.25 (95% CI, 1.01-1.54) for moderate intellectual disability, and 1.91 (95% CI, 1.47-2.48) for severe/profound intellectual disability. After the exclusion of individuals with neurodevelopmental and neurologic comorbidity, intellectual disability remained significantly associated with increased risks of CVD.

CONCLUSIONS: Individuals with intellectual disability had increased risks of early-onset CVD, in particular, for cerebrovascular disease, stroke, heart failure, and deep vein thrombosis, and the risks also increased with the severity of intellectual disability. Our findings highlight the awareness of increased risks of CVD in intellectual disability patients.

READING 2 – CARDIOVASCULAR COMPLICATIONS OF DOWN SYNDROME

Dimopoulos K,^{#,1,2} Constantine A,^{#,1,2} Clift P,³ Condliffe R,⁴ Moledina S,^{5,6} Jansen K,^{7,8} Inuzuka R,⁹ Veldtman GR,¹⁰ Cua CL,¹¹ Tay ELW,¹² Opotowsky AR,¹³ Giannakoulas G,¹⁴ Alonso-Gonzalez R,^{15,16} Cordina R,¹⁷ Capone G,^{18,19} Namuyonga J,^{20,21} Scott CH,²² D'Alto M,²³ Gamero FJ,²⁴ Chicoine B,²⁵ Gu H,²⁶ Limsuwan A,²⁷ Majekodunmi T,²⁸ Budts W,²⁹ Coghlan G,³⁰ Broberg CS³¹; for Down Syndrome International (DSi). Cardiovascular Complications of Down Syndrome: Scoping Review and Expert Consensus. *Circulation*. 2023 Jan 31;147(5):425-441. PMID: 36716257.

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Author information:

¹Adult Congenital Heart Centre and Centre for Pulmonary Hypertension, Royal Brompton Hospital, Royal Brompton and Harefield Hospitals, Guy's and St Thomas' NHS Foundation Trust, London, United Kingdom (K.D., A.C.)

²National Heart and Lung Institute, Imperial College London, United Kingdom (K.D., A.C.)

³Department of Cardiology, Queen Elizabeth Hospital Birmingham, United Kingdom (P.C.)

⁴Pulmonary Vascular Disease Unit, Royal Hallamshire Hospital, Sheffield, United Kingdom (R.C.)

⁵National Paediatric Pulmonary Hypertension Service UK, Great Ormond Street Hospital for Children NHS Foundation Trust, London, United Kingdom (S.M.)

⁶Institute of Cardiovascular Science, University College London, United Kingdom (S.M.)

⁷Adult Congenital and Paediatric Heart Unit, Freeman Hospital Newcastle Upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne, United Kingdom (K.J.)

⁸Population Health Sciences Institute, Newcastle University, Newcastle upon Tyne, United Kingdom (K.J.)

⁹Department of Pediatrics, The University of Tokyo Hospital, Japan (R.I.)

¹⁰Scottish Adult Congenital Cardiac Service, Golden Jubilee Hospital, Glasgow, Scotland, United Kingdom (G.R.V.)

¹¹The Heart Center, Nationwide Children's Hospital, Columbus, OH (C.L.C.)

¹²Department of Cardiology, National University Hospital Singapore (E.T.L.W.)

¹³The Heart Institute, Department of Pediatrics, Cincinnati Children's Hospital, University of Cincinnati College of Medicine, OH (A.R.O.)

¹⁴Department of Cardiology, AHEPA University Hospital School of Medicine, Aristotle University of Thessaloniki, Greece (G.G.)

¹⁵Division of Cardiology, Toronto General Hospital, University Health Network, Peter Munk Cardiovascular Center, University of Toronto, Canada (R.A.-G.)

¹⁶Toronto Adult Congenital Heart Disease Program, Canada (R.A.-G.)

¹⁷Department of Cardiology, Royal Prince Alfred Hospital and Sydney Medical School, University of Sydney, New South Wales, Australia (R.C.)

¹⁸Down Syndrome Clinical and Research Center, Kennedy Krieger Institute, Baltimore, MD (G. Capone)

¹⁹Johns Hopkins School of Medicine, Baltimore, MD (G. Capone)

²⁰Department of Paediatric Cardiology, Uganda Heart Institute, Kampala (J.N.)

²¹Department of Paediatrics and Child Health, Makerere University College of Health Sciences, Kampala, Uganda (J.N.)

²²University Hospital of the West Indies, Kingston, Jamaica (C.H.S.)

²³Department of Cardiology, University "L. Vanvitelli" – Monaldi Hospital, Naples, Italy (M.D.)

²⁴Department of Cardiovascular Surgery, Benjamin Bloom Children's Hospital, El Salvador (F.J.G.)

²⁵Advocate Medical Group Adult Down Syndrome Center, Park Ridge, IL (B.C.)

²⁶Department of Pediatric Cardiology, Beijing Anzhen Hospital, Capital Medical University, China (H.G.)

²⁷Division of Pediatric Cardiology, Department of Pediatrics, Ramathibodi Hospital, Mahidol University, Bangkok, Thailand (A.L.)

²⁸Department of Cardiology, Euracare Multi-specialist Hospital, Nigeria (T.M.)

²⁹Division of Congenital and Structural Cardiology, University Hospitals Leuven, and Department of Cardiovascular Science, Catholic University Leuven, Belgium (W.B.)

³⁰Department of Cardiology, Royal Free Hospital, London, United Kingdom (G. Coghlan)

³¹Knight Cardiovascular Institute, Oregon Health and Science University, Portland (C.S.B.)

[#]Contributed equally Collaborators: Dimopoulos K, Constantine A, Clift P, Condliffe R, Moledina S, Jansen K

ABSTRACT

Cardiovascular disease is a leading cause of morbidity and mortality in individuals with Down syndrome. Congenital heart disease is the most common cardiovascular condition in this group, present in up to 50% of people with Down syndrome and contributing to poor outcomes. Additional factors contributing to cardiovascular outcomes include pulmonary hypertension; coexistent pulmonary, endocrine, and metabolic diseases; and risk factors for atherosclerotic disease.

Moreover, disparities in the cardiovascular care of people with Down syndrome compared with the general population, which vary across different geographies and healthcare systems, further contribute to cardiovascular mortality; this issue is often overlooked by the wider medical community.

This review focuses on the diagnosis, prevalence, and management of cardiovascular disease encountered in people with Down syndrome and summarises available evidence in 10 key areas relating to Down syndrome and cardiac disease, from prenatal diagnosis to disparities in care in areas of differing resource availability.

All specialist and nonspecialist clinicians providing care for people with Down syndrome should be aware of best clinical practice in all aspects of care of this distinct population.

READING 3 – INTELLECTUAL DISABILITY AND COVID-19

Ying J,¹ Tan GMY,¹ Zhang MW.² Intellectual disability and COVID-19: A bibliometric review. *Front Psychiatry*. 2022 Nov 9;13:1052929. . PMID: 36440400.

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Author information:

¹East Region, Institute of Mental Health, Singapore, Singapore

²Central Region, Institute of Mental Health, Singapore, Singapore

ABSTRACT

BACKGROUND: During the COVID-19 pandemic, the vulnerabilities of certain groups of people have been highlighted, such as people with intellectual disability (PWID). Although related research on PWID has developed rapidly during the COVID-19 pandemic, the quantitative analysis of those research results has not been systematically performed through bibliometric analysis. Bibliometric analysis is a useful and rigorous method to explore large volumes of research data, and it allows researchers to extract quantitative information on distribution by author, time, country, and journal.

AIM: The aim of the present study is to comprehensively analyse the current status and developing trends in publications on ID research related to and conducted during the COVID-19 pandemic.

METHODS: A bibliometric analysis was performed using the Web of Science database. Biblioshiny software was used to analyse and visualise the following information: main information of dataset, annual scientific production, journals that published the most relevant sources, most-cited authors, most-cited countries, most-cited global documents, word-cloud of keywords authors have used, and both the co-occurrence and co-citation networks.

RESULTS: A total of 450 publications were included. The average number of citations per document was 5.104. Among the top three journals, *Journal of Applied Research in Intellectual Disabilities* published 32 articles, *Journal of Intellectual Disability Research* published 29 articles, and *British Journal of Learning Disabilities* published 17 articles. The article with the title "COVID-19 and People with Intellectual Disability: Impact of a Pandemic" was the most cited with total of 144 citations. The United Kingdom had the most publications and had strong cooperative relationships with the United States, Canada, and Australia. The most popular keywords included "mental health", "autism", "developmental disability", and "lockdown". Thematic map analysis identified several possible clusters, including telemedicine, physical activities, and mental health.

CONCLUSION: The present study provides a better understanding in this research field and may help clinicians, researchers, and stakeholders to obtain more comprehensive view of ID and COVID-19. The insights gained from this analysis could inform future research.

READING 4 – MOST CITED PAPERS ON SPECIAL OLYMPICS

Kho S,^{1,2} Ansari P,³ John J,⁴ Brooke M.⁵ The Top 50 Most Cited Articles on Special Olympics: A Bibliometric Analysis. *Int J Environ Res Public Health*. 2022 Aug 16;19(16):10150. PMID: 36011782.

doi: 10.3390/ijerph191610150. PMID: 36011782. Free full text.

Author information:

¹Centre for Sport and Exercise Sciences, Universiti Malaya, Kuala Lumpur 50603, Malaysia

²Disability Sport Research Centre, Universiti Malaya, Kuala Lumpur 50603, Malaysia

³DCU Business School, Dublin City University, D09Y5NO Dublin, Ireland

⁴Department of Restorative Dentistry, Faculty of Dentistry, Universiti Malaya, Kuala Lumpur 50603, Malaysia

⁵Centre for English Language Communication, National University of Singapore, Singapore 117511, Singapore

ABSTRACT

The Special Olympics was established in 1968 to “provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities”. It has gained recognition in the field of sports and healthcare of persons with intellectual disability, with a large number of dedicated researchers and institutions all over the world. However, there is an urgent need to analyse the progress and current status of this research field to identify knowledge gaps and develop this discipline.

The aim of this study was to analyse the scientific production of the Special Olympics and report the bibliometric characteristics of the top 50 most cited Special Olympics publications. A systematic search was conducted on the Scopus database and bibliometric data were extracted and analysed.

The top 50 publications received 1,632 citations. A total of 138 authors (63 female and 75 male) contributed to these publications. The two main areas of study were the physical health of Special Olympics athletes (n=27) and the psychosocial health of athletes (n=12).

READING 5 – PARTICIPATION IN EVERYDAY ACTIVITIES FOR CHILDREN WITH INTELLECTUAL DISABILITIES IN CHINA

Granlund M,¹ Huus K,¹ Wang L,² Shi L.^{1,2} Barriers and facilitators to participation in everyday activities for children with intellectual disabilities in China. *Child Care Health Dev*. 2023 Mar;49(2):346-356. PMID: 36001483

doi: 10.1111/cch.13052. PMID: 36001483. Free full text

Author information:

¹CHILD Research group, Swedish Institute of Disability Research, School of Health and Welfare, Jönköping University, Jönköping, Sweden

²School of Nursing, Tianjin Medical University, Tianjin, China

ABSTRACT

BACKGROUND: Children with intellectual disabilities (IDs) are vulnerable and participate less in everyday activities compared to their peers with typical development. This study aimed to identify barriers and facilitators related to the participation in everyday activities of children with IDs in China.

METHODS: Twenty semi-structured interviews were conducted with primary caregivers of children with IDs from special schools in Tianjin, China. The data were transcribed and analysed using inductive qualitative content analysis.

RESULTS: Four categories of barriers to participation in everyday activities for children with IDs were identified: insufficient knowledge, attitudes, and skills in primary caregivers; ID-related characteristics of children; stigma and Chinese culture; and lack of support from society. Four categories describing facilitators of participation in everyday activities for children with IDs were also identified: the optimistic attitude of the primary caregiver; adequate family support; active environment in school and policy; and attractive characteristics of children with IDs.

CONCLUSIONS: The findings in this study add knowledge of important barriers and facilitators affecting the participation of children with IDs in everyday activities in China. The primary caregivers' voices need to be heard by government and society. Appropriate and effective changes in family-oriented services and the legal, social, political, and economic context of the child welfare management system for the scale-up of improving participation should be implemented for children with IDs.

READING 6 – EXPOSURE TO COVID-19 INFECTION AMONG PEOPLE WITH DISABILITIES IN SOUTH KOREA

Jeon WH,¹ Oh IH,¹ Seon JY,² Kim JN,³ Park SY.⁴ Exposure to COVID-19 Infection and Mortality Rates Among People With Disabilities in South Korea. *Int J Health Policy Manag.* 2022 Jun 27;11(12):3052-9. PMID: 35942968.

doi: 10.34172/ijhpm.2022.6996. PMID: 35942968. Free full text.

Author information:

¹Department of Preventive Medicine, School of Medicine, Kyung Hee University, Seoul, South Korea

²Health Insurance Research Institute, National Health Insurance Service, Wonju, South Korea

³Department of Health Services Management, School of Management, Kyung Hee University, Seoul, South Korea

⁴Department of Medical Education and Medical Humanities, School of Medicine, Kyung Hee University, Seoul, South Korea

ABSTRACT

BACKGROUND: With the delayed eradication of COVID-19, people with disabilities, a socially vulnerable class of individuals, face aggravated hardships caused by a pause in support services and lack of care due to stricter social distancing policies combined with the challenges of their disabilities. Given this background, we aim to investigate COVID-19 infection and mortality rates among people with disabilities, who face heightened physical and mental health threats amidst the COVID-19 pandemic.

METHODS: Gender, age, health insurance premiums, the Charlson Comorbidity Index (CCI), the severity of the disability, and the type of disability were compared among people with disabilities who had been infected with or died from COVID-19 using the nationally representative National Health Insurance Service (NHIS)-COVID-19 database (DB).

RESULTS: We found that the COVID-19 infection rate was higher among those with low income, those with severe disability, and those with "other" disabilities (i.e., speech disabilities, hepatic dysfunction, respiratory dysfunction, facial disfigurement, intestinal fistular/urinary disability, epilepsy, intellectual disability, autistic disorder, and mental disorders). The mortality rate was markedly higher (i.e., 15.90 times higher, odds ratio [OR]: 15.90, 95% confidence interval [CI]: 6.16-41.06) among people aged 80 years or older as compared with those aged 60 years or younger. The odds for mortality were 2.49 times higher (OR: 2.49, 95% CI: 1.33-4.64) among people with severe disabilities as compared with mild disabilities.

CONCLUSION: Among people with disabilities, we found that COVID-19 infection rates differed according to income level, severity of the disability, and disability type, while the COVID-19 mortality rates differed according to age and severity of the disability.

READING 7 – FORMULATION, EXISTING PROBLEMS, AND PRACTICAL EFFECTS OF FITNESS EXERCISE PRESCRIPTIONS FOR PEOPLE WITH INTELLECTUAL DISABILITIES

Yan Z,¹ Yan P,² Qin C,³ Luo J.⁴ Review on the Formulation, Existing Problems, and Practical Effects of Fitness Exercise Prescriptions for People With Intellectual Disabilities. *Front Public Health*. 2022 Jul 22;10:936830. PMID: 35937213.

doi: 10.3389/fpubh.2022.936830. PMID: 35937213. Free full text.

Author information:

¹School of Physical Education, Chongqing University of Posts and Telecommunications, Chongqing, China

²The College of Exercise Medicine, Chongqing Medical University, Chongqing, China

³Chongqing Institute of Sport Science, Chongqing, China

⁴College of Physical Education, Southwest University, Chongqing, China

ABSTRACT

Compared with normal people, patients with intellectual disability have poor cardiopulmonary and muscle fitness levels, and their daily physical activity generally cannot reach the "guideline-recommended amount", which increases the risk of obesity and cardiovascular disease in this group.

From the perspective of six elements of exercise prescription (frequency, intensity, time, form of exercise, amount of exercise, and progressive rate), this paper systematically reviews the current situation of the formulation and implementation of exercise prescription for patients with intellectual disabilities.

The results show that the design idea of aerobic fitness exercise prescription for patients with intellectual impairment follows the six-element paradigm, but the insufficient recommended amount of each element is a common problem. In the design of muscle fitness exercise prescription, due to the differences of different exercise forms, the description of the six elements is very inconsistent. Although most prescription execution effects show that improving cardiopulmonary and muscle fitness is beneficial, there is a great debate on whether it improving body composition is beneficial.

People with intellectual disabilities are highly heterogeneous groups. In the initial stage of exercise intervention, the elements of exercise prescription need to be adjusted individually to obtain sustainable positive benefits.

READING 8 – IMPACT OF SOCIAL SUPPORT FOR MOTHERS AS CAREGIVERS OF CEREBRAL PALSY IN JAPAN

Moriwaki M,¹ Yuasa H,² Kakehashi M,³ Suzuki H,⁴ Kobayashi Y.⁵ Impact of social support for mothers as caregivers of cerebral palsy children in Japan. *J Pediatr Nurs*. 2022 Mar-Apr;63:e64-e71. PMID: 34736819.

doi: 10.1016/j.pedn.2021.10.010. PMID: 34736819. Free full text.

Author information:

¹Quality Management Center, Tokyo Medical and Dental University Hospital, 1-5-45 Yushima, Bunkyo-ku, Tokyo 113-8510, Japan. Electronic address: mmoriwaki.qmc@tmd.ac.jp

²Japan Council for Quality Health Care, 1-4-17, Toyo Bldg., Kandamisaki-cho, Chiyoda-ku, Tokyo 101-0061, Japan. Electronic address: h-yuasa@jcqhc.or.jp

³Graduate School of Biomedical and Health Sciences, Hiroshima University, 1-2-3 Kasumi, Minami-ku, Hiroshima City, Hiroshima 734-8553, Japan. Electronic address: kakehashi@hiroshima-u.ac.jp

⁴Japan Council for Quality Health Care, 1-4-17, Toyo Bldg., Kandamisaki-cho, Chiyoda-ku, Tokyo 101-0061, Japan. Electronic address: hideaki-suzuki@jcqhc.or.jp

⁵Department of Public Health, Graduate School of Medicine, The University of Tokyo, 7-3-1 Hongo Bunkyo-ku, Tokyo 113-17 0033, Japan. Electronic address: yasukik@m.u-tokyo.ac.jp

ABSTRACT

PURPOSE: Social supports are critical to alleviate the psychological and physical burden of primary caregivers of children with disabilities. This study aims to (1) clarify how cerebral palsy in children affects caregiving burden of the mother, and (2) identify the social supports that can effectively reduce that burden.

DESIGN AND METHODS: This is a cross-sectional study in which mothers of children with cerebral palsy completed questionnaires and provided data regarding their child's condition, family support, social support usage, degree of satisfaction with supports, and caregiving burden.

RESULTS: We analysed responses from 1,190 mothers. Support usage, particularly of home-visit nursing, home care, home-visit rehabilitation, and mobility support, was higher in severely burdened groups. However, the proportion of satisfaction with social support in groups with light or no burden were higher, particularly in home care, home-visit rehabilitation, training/treatment, and short stays. Mothers whose children have an intellectual disability and gross exercise ≥ 1 in addition to tube feeding or intravenous nutrition especially felt a strong sense of burden. The most effective measure in reducing mother's sense of burden was short stays.

CONCLUSIONS: Mothers with children who can move and have an intellectual disability felt more burden compared with mothers of bedridden children. The findings clarify that supports, such as home care and short stays, have a significant impact on reducing the mother's sense of burden.

PRACTICE IMPLICATIONS: Due to the large sample size, we believe that the results can inform efforts to increase social support for caregivers.

READING 9 – PHYSICAL ACTIVITY AND SEDENTARY BEHAVIOUR AMONG CHILDREN AND ADOLESCENTS WITH INTELLECTUAL DISABILITIES DURING THE COVID-19 LOCKDOWN IN CHINA

Yuan YQ,¹ Ding JN,² Bi N,³ Wang MJ,⁴ Zhou SC,⁵ Wang XL,⁶ Zhang SH,⁷ Liu Y,^{8,9} Roswal G.¹⁰ Physical activity and sedentary behaviour among children and adolescents with intellectual disabilities during the COVID-19 lockdown in China. *J Intellect Disabil Res.* 2022 Dec;66(12):913-923. PMID: 34730262

doi: 10.1111/jir.12898. PMID: 34730262. Free full text.

Author information:

¹College of Sports and Health, Shandong Sport University, Jinan, China

²Department of Physical Education, Fujian Agriculture and Forestry University, Fuzhou, China

³School of Sports and Physical Education, Shandong Sport University, Rizhao, China

⁴School of Chinese WuShu, Shandong Sport University, Rizhao, China

⁵School of Physical Education, Shanxi University, Taiyuan, China

⁶Graduate School, Harbin Sport University, Harbin, China

⁷Department of Physical Education, China Disabled Persons' Federation, Beijing, China

⁸Department of Physical Education, Shandong Jianzhu University, Jinan, China

⁹Department of Physical Education, Shandong University of Traditional Chinese Medicine, Jinan, China

¹⁰School of Health Professions and Wellness, Jacksonville State University, Jacksonville, AL, USA

ABSTRACT

BACKGROUND: In the wake of the COVID-19 pandemic, preliminary research has reported a significant decline in physical activity (PA) and an increase in sedentary behaviour (SB) among typically developed children and adolescents. Limited research has looked at the current situation of PA and SB during this pandemic among children and adolescents with intellectual disabilities (ID). This study investigated the situations about PA and SB among school-aged children and adolescents with ID on China's mainland during the COVID-19 outbreak.

METHODS: In total, 837 parents of children and adolescents (ages 6-18 years) with ID from 15 special education schools of Shandong Province in China were recruited through convenience sampling in the study. Parents reported PA and SB among children and adolescents with ID through the Children's Leisure Activities Study Survey-Chinese version (CLASS-C) online questionnaires.

RESULTS: From parents' reports, Chinese children and adolescents with ID during the COVID-19 pandemic participated in approximately 10 min of moderate-to-vigorous physical activity, and engaged in approximately 530 min of SB every day. Meanwhile, only 17.4% of children and adolescents with ID were able to achieve the recommendation of 60 min of daily moderate-to-vigorous physical activity and 76.1% of children and adolescents with ID spent more than 2 h on SB per day. Additionally, the problems of decreased PA and excessive SB were more prominent in older adolescents with ID compared with younger children with ID.

CONCLUSION: In China, the low level of PA and high level of SB is particularly evident in children and adolescents with ID during the outbreak of COVID-19. The vast majority of children and adolescents with ID did not meet the recommended amount of PA while undergoing excessive SB under the long-term home quarantine environment. Therefore, immediate attention and great effort should be made to deal with this severe situation among this vulnerable population in the mainland of China.

READING 10 – ADVERSE OUTCOMES AFTER MAJOR SURGERY IN CHILDREN WITH INTELLECTUAL DISABILITY

Huang SY,^{1,2} Cherg YG,^{1,2} Chang CC,^{2,3,4} Lin CS,^{2,3,4} Liao CC,^{2,3,4,8,9,10} Chen TL,^{2,4,7} Lin JA,^{2,7,8} Yeh CC.^{5,6}
Adverse outcomes after major surgery in children with intellectual disability. *Dev Med Child Neurol.* 2021 Feb;63(2):211-217. PMID: 33131081

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Author information:

¹Department of Anesthesiology, Shuang Ho Hospital, Taipei Medical University, New Taipei City, Taiwan

²Department of Anesthesiology, School of Medicine, College of Medicine, Taipei Medical University, Taipei, Taiwan

³Department of Anesthesiology, Taipei Medical University Hospital, Taipei, Taiwan

⁴Anesthesiology and Health Policy Research Center, Taipei Medical University Hospital, Taipei, Taiwan

⁵Department of Surgery, China Medical University Hospital, Taichung, Taiwan

⁶Department of Surgery, University of Illinois, Chicago, IL, USA

⁷Department of Anesthesiology, Wan Fang Hospital, Taipei Medical University, Taipei, Taiwan

⁸Center of Regional Anesthesia and Pain Medicine, Wan Fang Hospital, Taipei Medical University, Taipei, Taiwan

⁹Research Center of Big Data and Meta-Analysis, Wan Fang Hospital, Taipei Medical University, Taipei, Taiwan

¹⁰School of Chinese Medicine, College of Chinese Medicine, China Medical University, Taichung, Taiwan

ABSTRACT

AIM: To evaluate outcomes after major surgery in children and adolescents with intellectual disability.

METHOD: We used 2004 to 2013 claims data from Taiwan's National Health Insurance programme to conduct a nested cohort study, which included 220,292 surgical patients aged six to 17 years. A propensity score matching procedure was used to select 2,173 children with intellectual disability and 21,730 children without intellectual disability for comparison. Logistic regression was used to calculate the adjusted odds ratios (ORs) and 95% confidence intervals (CIs) of the postoperative complications and 30-day mortality associated with intellectual disability.

RESULTS: Children with intellectual disability had a higher risk of postoperative pneumonia (OR 2.16, 95% CI 1.48-3.15; $p < 0.001$), sepsis (OR 1.67, 95% CI 1.28-2.18; $p < 0.001$), and 30-day mortality (OR 2.04, 95% CI 1.05-3.93; $p = 0.013$) compared with children without intellectual disability. Children with intellectual disability also had longer lengths of hospital stay ($p < 0.001$) and higher medical expenditure ($p < 0.001$) when compared with children with no intellectual disability.

INTERPRETATION: Children with intellectual disability experienced more complications and higher 30-day mortality after surgery when compared with children without intellectual disability. There is an urgent need to revise the protocols for the perioperative care of this specific population.

WHAT THIS PAPER ADDS: Surgical patients with intellectual disability are at increased risk of postoperative pneumonia, sepsis, and 30-day mortality. Intellectual disability is associated with higher medical expenditure and increased length of stay in hospital after surgical procedures. The influence of intellectual disability on postoperative outcomes is consistent in both sexes and those aged 10 to 17 years. Low income and a history of fractures significantly impacts postoperative adverse events for patients with intellectual disability.